



Data Sharing and Intellectual Capital Working Group Teleconference

June 24, 2004	2:00 pm EDT
Attendees:	<p><i>Attendees:</i></p> <p>Arizona: David Mount City of Hope: Joyce Niland Jackson Laboratory: Carol Bult Oregon Health and Science University: Ed Quick Thomas Jefferson University—Kimmel: Jack London University of Minnesota: Don Connelly Washington University—Siteman: Mark Watson U Penn – Howard Bilofski Fox Chase – Pat Harsche-Weeks; Amin Chisti NCI - Wendy Patterson; Leslie Derr BAH - Phan Winter</p>
Introduction	<p>Wendy Patterson opened the meeting and reviewed agenda. Response to the June 10th meeting notes was positive.</p>
Report from Liaisons	<p><u>Training</u> (Ed Quick -OHSU): There has not been a general meeting of the entire Training Working Group since the DSIC WG's last call (6/10/04). During the Developer SIG's last meeting, they discussed standard training practices and continued to explore conferencing options.</p> <p><u>Integrative Cancer Research (ICR)</u> (Terry Braun -University of Iowa – Holden): Terry Braun was absent, so there was no report.</p> <p><u>Clinical Trials Workspace (CTWS)</u> (Don Connelly - University of Minnesota): The CTWS discussed contract issues; the group was worried about the slow progress on this matter. The group is focused on standard approaches and methods and the use of these standards. Don reported that it is still too early for the CTWS to focus on IP issues. The group has made good progress in developing structured protocol documents and is planning a face-to-face meeting July 19 – 20 to discuss the document.</p>



	<p><u>Tissue Banks and Pathology Tools Workspace</u> (Mark Watson - Washington University - Siteman): The TBPT WS will meet next Tuesday (6/29/04) to discuss responses to their survey. This group is trying to determine which centers need databases built from the ground up and which centers already have systems running that need to be adapted to caBIG standards. The TBPT WS had initially planned to establish a data sharing SIG but dropped the idea since the DSIC WG is already covering these issues.</p>
Report on IP POCs	<p>The following are confirmed IP POCs for the DSIC WG:</p> <ul style="list-style-type: none">• <u>Iowa</u>: Daniel G. Happe• <u>City of Hope</u>: Larry Couture• <u>Washington University – Siteman</u>: Jon Kratochvil• <u>Thomas Jefferson - Kimmel</u> - Katherine Chou• <u>University of Arizona</u>- Lee Anne T. Peters• <u>OHSU</u> - David Cepoi; Jessica Zeaske• <u>Fox Chase</u> - Pat Harsche-Weeks• <u>Jackson Labs</u> -David Einhorn• <u>U Penn</u> - Terry J. Fadem• <u>University of Minnesota</u> - Michael F. Moore• <u>Fred Hutchinson</u> - Paul J. Brynes <p>Phan has requested contact information from caBIG/DSIC participants for the following institutions and is still waiting for responses from:</p> <ul style="list-style-type: none">• University of Michigan• University of Pittsburgh• JHU <p>Phan has not been able to reach the caBIG participant for Cold Spring Harbor (Lincoln Stein).</p>
Update on Survey	<p>Wendy asked for comments to Mark Watson's revisions to the</p>



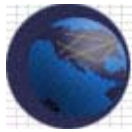
Development

survey. Pat thought that the changes were very useful; the revised questions are reasonable and likely to get information from respondents within a month. Mark pointed out that the existing questions relate to specimens and the group still needs to develop questions for other items such as agents and software tools. Wendy asked if anyone else would volunteer to share the work with Mark. There was no responses, so Mark agreed to develop the remaining the questions with input from Wendy. Howard volunteered to review and comment on Mark's new questions. The revised questionnaire will be re-circulated before the next call on July 8th.

Joyce Niland expressed concern that the survey may be too open-ended. She thought that additional input from caBIG community should be obtained to make sure we are on the right track. Leslie Derr suggested sending a draft of the survey to the Strategic Planning Working Group.

Joyce thought that the survey should convey more precisely the types of data cancer centers will be expected to share. She suggested using a "straw man" approach with concrete examples to focus the respondents, who will be the tech transfer professionals at individual cancer centers. She thought it was important that the survey accurately describe caBIG to the respondents, both in terms of its vision and the mechanics. She said the group should be careful not to give the impression of encroaching on individual cancer center agreements but rather try to assure centers that we can help them share data in connection with caBIG efforts while complying with their obligations imposed by existing agreements

Wendy responded that the scenarios should be targeted to the respondents who are tech transfer professionals and used to negotiating agreements with data sharing provisions. Pat agreed and suggested using an example in which tools developed by caBIG participants need to be shared freely without restrictions. Mark suggested taking the straw man approach even further by using a mock agreement in the survey and observing which issues arise. He thought that a model contract might emerge through an iterative process in which the DSIC WG and cancer center tech transfer offices refine the model agreement into a version that most participants could accept. Pat observed that she has never used the same agreement twice but was in favor of a model agreement that could serve as a point of departure.



Joyce cautioned that Mark's approach would raise issues beyond the provisions in the agreements, such as matters relating to publications and the patentability of certain things. Mark emphasized the need to be quantitative in order to see the extent of difficulties and issues confronted by each Center. The group concluded that it was a good idea to use scenarios as an introduction to Mark's revised questions. Joyce agreed to write an introductory paragraph with several specific scenarios to which some of the survey questions might be targeted

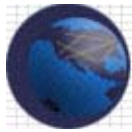
Howard brought up the question he raised during the last meeting regarding the level of effort required to complete surveys and the availability of funding for this activity. Wendy responded that this issue has been raised but did not have any answers yet. Howard suggested that if no resources are available, then the DSIC WG would have to scale back its expectations for the survey. Wendy thought that it was best to review the next iteration of the survey before determining how much effort will be required.

Joyce and Mark stated that they would try to complete the introductory material and new sets of questions within 1-2 weeks.

Data Access Hierarchy

Howard thought that the hierarchy as currently formulated was limiting. It does not address cases in which access to certain types of data need to be restricted or in which a recipient may not want access to certain data to avoid tainting an experiment. Rather than create new tiers within the hierarchy, he recommended adding more dimensions that show the roles and responsibilities of those accessing the data. He thought that the Architecture WS should be asked to develop a mechanism to capture the richness of these sharing relationships/practices.

Howard expressed concern that if the data hierarchy is too detailed, then some participants may protest that we did not address their specific case. Mark suggested that this could be an iterative process and that we might not know what's wrong with the details until we got constructive feedback. Howard compared the process to writing a legal agreement. Each subsequent version of an agreement becomes a new construct in which the only common element left may be the language itself. Howard agreed to try to write a paragraph to capture his



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	<p>ideas.</p> <p>Joyce suggested that we ask for examples of successful agreements that have worked from the standpoint of promoting data sharing. The group agreed and recommended that this request be added to the survey.</p> <p>Wendy suggested that we not get caught up in the idea of a hierarchy and that it was also possible to think in terms of “tiers” of data access.</p>			
“Open Source” Articles Discussions	In the interest of time, Wendy suggested that this discussion be tabled until next call. Pat said that she found both articles very stimulating and highly recommended them to the group.			
Items for Next Teleconference: July 8th	<p>Discuss new survey questions and introductory scenarios</p> <p>Discuss “open source” articles</p> <p>Continue discussion on the multi-dimensionality of data access tiers/hierarchy.</p> <p>NOTE: Wendy will not be available on July 22nd and proposed canceling the teleconference scheduled for that day.</p>			
Action Items:				
	Name Responsible	Action Item	Date Due	Notes
	Mark Watson	New survey questions	7/6/2004	
	Joyce Niland	Introductory paragraph(s)	7/6/2004	
	Howard Bilofski	Description of data access dimensions	7/6/2004	
	All	Read “open source” articles	7/8/2004	